Conclusions: Results suggest that the CF Foundation’s new web pages related to NBS are achieving the intended outcomes for most parents. Additional minor revisions may further enhance the quality of the web pages.

This project was supported by a grant from the Cystic Fibrosis Foundation.

Table: Web Page Usage in 2012

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SCARY STUFF: PARENTS’ SELF-SEEKING OF INFORMATION VIA THE INTERNET FOLLOWING THEIR CHILD’S DIAGNOSIS WITH CYSTIC FIBROSIS

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Objective: To explicate the information seeking behaviours of parents of an infant diagnosed with CF.

Background: The diagnosis of their child with cystic fibrosis (CF) is a devastating event compounded for most parents by CF being a hitherto unknown entity. Information and education are vital to their processing what is CF, its implications for their child and family, and their efficacious engagement with care. While health carers may plan a metered presentation of information and education, parents reportedly pursue further facts for themselves as they seek to process their child’s health status.

Method: This qualitative inquiry was conducted to inform the development of a national survey of parent information needs beyond newborn screening (NBS). Semi-structured interviews were conducted with parents (n=10) of infants aged from 1 to 3 years diagnosed with CF following NBS. Interviews were recorded, transcribed and thematically analysed.

Results: Following diagnosis, participants reported embarking on a quest to find out all they could about this disease, which some had heard but had little reliable integral knowledge. Their pursuit was born of a desire to “get everything we could” and “to know the answers.” There was also a desire to supplement formal hospital literature, described as outdated, and a “get everything we could” and “to know the answers.” There was also a desire to supplement formal hospital literature, described as outdated, and a "get everything we could" and "to know the answers.”

Conclusions: This is the first teaching model which has been developed for use in the ambulatory care setting which specifically engages the MD team in the teaching of medical learners. Adoption of this model may allow for an enhanced educational experience for medical learners in the CF clinic, while maintaining efficiency. Further assessment of these outcomes during the implementation phase will be required.

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SEXY HEALTH: WHAT DO ADOLESCENTS KNOW?

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Background: Knowledge deficits related to sexual health exist among adolescents with cystic fibrosis. Research has shown a clear lack of sexual and reproductive health knowledge among female patients with CF (1). Knowledge contributes to behavioral capability and is therefore a part of the framework of behavioral requirements for self-management. Research has demonstrated positive responses to age-appropriate educational opportunities with a sound theoretical base (2).

Aim: The aim of this study is to determine if education utilizing a sexual health teaching tool improves the knowledge of adolescents regarding sexual health.

Method: This project is a one group pre-test/post-test design. A knowledge survey was completed as a pilot to assess knowledge deficits among adolescents 14-21 years old. The survey questions addressed the definition...